The Road Unknown: Meet Jean Davidson

ET Research Studies are Recruiting

Hot Topic: Marijuana and ET

Straight Talk on Vocal Tremor
Thoughts from the Executive Director

This issue is full of inspirational stories of people living their lives with ET and making a difference. We were positively moved reading the stories that poured in from people working to increase awareness about ET in their own communities. We were touched by how much support they received in return and what everyone was able to accomplish. Each person is an example of how harnessing the power and energy inside of us can cause tremendous positive results and enable us to become so much more than we once thought we could become.

This issue contains two excellent well written articles; one concerning the medicinal use of marijuana and the second, a review of vocal tremor and the options for treatment. Both articles help us understand the difficulties that each present. Over the last few months, we received many questions about vocal tremor and of course the treatment of ET with marijuana. We hope these articles answer many of your questions, although it seems in regard to marijuana there are many questions yet to be answered. Perhaps this will encourage more research to help find the many more questions that need answered.

This issue also features a very special lady, Jean Davidson, the granddaughter of Walter Davidson, one of the four founders and the first president of Harley-Davidson. Her father, Gordon Davidson, was Vice President of Manufacturing. Jean shares her inspiring story of living with ET, experiencing the loss of a grandchild and finding a way to use her grief and loss to help others. We thank Jean for telling us her story and sharing her experiences with us. We hope that someday she will be an active participant in helping us find better treatments and creating greater awareness for ET.

Please don’t pass up the opportunity to participate in some very important research and also read about the groundbreaking work that Dr. Calon and his colleagues are doing in Québec City, Canada. They have identified two proteins, LINGO 1 and LINGO 2 that may be linked to movement disorder and especially the revelation that there is a higher concentration of LINGO 1 in people with essential tremor. Many of you made this research possible with your donations and continued support of the IETF as it was funding from the IETF that supported his work. We look forward to hearing more from Dr. Calon as he continues his research.

And finally, we will all greatly miss Dr. Bakay. He was a very integral part of our Medical Advisory Board by always participating and encouraging more research for ET. I hope you will take the time to read about his life because he was a very special individual.

And of course, the IETF staff and board of directors all want to say thank you for a great ET Awareness Month and for your tremendous outreach. We can’t thank you enough for all your support, fundraising effort and participation. Thanks to you more research will be possible and a greater awareness effort can be accomplished next year! You can count on it!

Sincerely,

Catherine Rice
Executive Director, IETF
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Jean Davidson finds strength in education

Cover Photo: Jean Davidson

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Please send comments, questions, and story ideas to: IETF Tremor Talk Editor, PO Box 14005, Lenexa, Kansas 66285-4005 USA or call toll free 888-387-3667 or email info@essentialtremor.org

This publication is not intended to provide medical advice or be a substitute for qualified medical care. Appropriate treatment for your condition should be obtained from your physician. The content of this publication offers information to those with essential tremor. The IETF does not endorse any product advertised in this publication unless otherwise stated.

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In Memory of Dr. Bakay

Roy A. E. Bakay, M.D., was a vital member of the IETF Medical Advisory Board for several years, and it is with great sorrow that we announce his passing. Dr. Bakay was a compassionate and skilled neurosurgeon, a caring father, a life companion, and a dear friend to many. He passed away in September 2013 after a long fight with stomach cancer. He is survived by his four children, Mark, Scott, Candace and Jacqueline Bakay and his first grandson, Maximillion, the son of Scott and Monica Bakay. The precious time that he had with Max was filled with joy.

Dr. Bakay was a leading authority on Parkinson’s disease and specialized in surgery for movement disorders. His research focused on neural tissue transplantation and gene therapy techniques that spanned a career of over 40 years. He also was instrumental in developing cutting-edge stereotactic surgery for Parkinson’s tremors. Dr. Bakay was listed as Chicago’s Top Doctors over eight times and won numerous awards including the AMA Physician Recognition Award, A. Watson Armour III and Sarah Armour Presidential Chair, Philip Gildenberg Award, and the Molly and Bernard Sanberg Memorial Award.

A graduate of Northwestern University Medical School, he continued his academic medical career authoring four books, 56 chapters, more than 153 journal articles, and 314 other publications. Dr. Bakay was a consummate physician and scientist, totally dedicated to improving the lives of his patients who suffered from life-altering movement disorders.

Dr. Bakay also lived a rich personal life outside the medical arena. He was a world traveler, and loved experiencing international food and culture. In recent years, he and his love Cheryl Morris shared many wonderful trips which, in spite of his infamous struggles with fashion, were filled with adventure, laughter and exploration. He was an avid deep sea fisherman and was a great teller of ‘big-fish’ stories. He also was big fan of all sporting events and grew to become a true supporter of Chicago sports teams.

He never shied away from providing his opinion of movies, sports and culture, and his humor and quiet, quick wit will be missed by all those who knew him.

“Those we hold most dear never truly leave us ... they live on in the kindnesses they showed, the comfort they shared and the love they brought into our lives.”

- Isabel Norton
Ask the Doctors

Have you ever left the doctor’s office only to realize you forgot to ask a question? It happens to us all. We asked our Medical Advisory Board about Edie’s question and here is what our experts had to say.

Q.

It is often noted that people with essential tremor don’t tremor while at rest or sleeping. What is the mechanism that causes the tremor to stop? Is there some process that goes on during rest or sleep that is not present during waking times?

- Edie D.
  IETF member
  Raleigh, NC

A.

I don’t think anyone knows for sure, Edie. We still do not quite understand what starts the tremor in ET and what controls the amplitude of the tremor. The suppression of the tremor during sleep and its enhancement by stress and anxiety are not specific to ET and occur also in Parkinson’s disease and other tremor disorders. It is possible that the reticular activating system, a brain structure that controls alertness, also affects regions involved in tremor generation and activation.

- Dr. Amos Korczyn
  Professor Emeritus, Department of Neurology, Tel Aviv University in Israel

One other thought that comes to mind, Edie, is that sleep affects the balance between the sympathetic (the part of the system that controls most of the body’s internal organs) and parasympathetic nervous systems (the complimentary part of the system that promotes digestion), favoring the latter. While ET has multiple mechanisms, sympathetic tone does play a part. It is no coincidence that one of the most successful ET medications (Propranolol) inhibits sympathetic tone while inhalers like Albuterol can exacerbate both ET and physiological tremor (the kind of tremor everyone has from time to time).

- Dr. Arif Dalvi
  Director of the Movement Disorders Program, Neuroscience Institute at Methodist Hospital in Merrillville, IN, and Clinical Associate Professor of Neurology, University of Chicago Pritzker School of Medicine in Glenview, IL

Got questions? We invite you to send in your questions to info@essentialtremor.org or call us (toll free) at 888.387.3667. Your question may be featured in the next Tremor Talk “Ask the Doctors”.

essentialtremor.org
How often do you think about how your voice sounds or how it feels when you speak? Normally, few of us think about our voices on a daily basis because speaking is usually effortless. In fact, many of us are unaware of our voices unless we have a cold and sound hoarse or we are in a noisy room and have to shout to be heard. But some people with essential tremor think about their voices all the time. They notice that their voices sound shaky when they speak. They feel that their voices are difficult to control and that speaking is tiring. These are the people who have vocal tremor, a voice disorder that affects approximately 18-30% of people with essential tremor. Fortunately, some people with vocal tremor can benefit from therapy with a speech-language pathologist (SLP) to learn how to make the voice sound less shaky and how to use less effort when speaking.

What Causes Vocal Tremor?
Many people assume that a shaky voice is caused by tremor within the larynx (the “voice box”). This is true for some people with vocal tremor. But vocal tremor can also be caused by tremor affecting the chest, abdomen, mouth, or throat. We use all of these parts of the body to speak. Before we speak, we take a breath and then we slowly release the breath to speak. We control the breath using our chest and abdominal muscles. As we release the breath, we also use muscles in the larynx to allow the vocal folds (often called the vocal cords) to vibrate and produce sound. In addition, we use muscles in the mouth and throat to shape the voice into sounds that can be understood as speech. Because muscles in all of these parts of the body are used to speak, tremor affecting any of these areas can make the voice sound shaky.

How is Vocal Tremor Treated?
The medications that are used to treat tremor affecting the arms and legs are not often effective in treating vocal tremor. But some people with vocal tremor benefit from injections of small amounts of botulinum toxin (Botox®) into the larynx, as discussed in the August 2013 issue of Tremor Talk. This can sometimes make the voice sound less shaky and can make it feel less effortful to speak. Unfortunately, this treatment does not help everyone with vocal tremor, and it may have some negative side effects including difficulty swallowing. For people who do benefit from Botox®, the effects are only temporary so the injections are typically repeated every few months. For these reasons, some people seek a different...
treatment approach for vocal tremor that involves therapy with an SLP.

**What is the Research on Therapy for Vocal Tremor?**
Recent research has demonstrated that therapy can help make the voice sound more stable and make it feel easier to speak for some people with vocal tremor. But more research is needed in this area to determine who the best candidates for therapy are and what the best treatment approaches are for these individuals. Because so many muscles are used to produce voice and because essential tremor can affect many different muscles, it can be challenging to study vocal tremor in people who have essential tremor. That is one of the reasons why researchers at the University of Arizona are using computer models to simulate vocal tremor involving the different parts of the body that are used to speak. Using these models, they can isolate tremor to one part of the speech mechanism or simulate combinations of tremor affecting multiple parts of the speech mechanism. They can then make adjustments to the voice and determine which ones reduce how shaky the voice sounds to listeners. The ultimate goal is to use these findings to help determine the most effective and efficient therapeutic approaches for treating vocal tremor.

**How Can I Try Therapy for Vocal Tremor?**
If you think that therapy might help you, ask your doctor about a referral to an SLP who specializes in voice. You may also visit www.asha.org/findpro or call (toll free) 800.638.8255 to find an SLP in your area. To determine if you would benefit from therapy, the SLP will ask you about the changes in your voice, listen to and record your voice, and watch the way you speak. The SLP will see if tremor affects your larynx, chest, abdomen, mouth, or throat while you speak. Depending on the results of the evaluation, the SLP might teach you ways to adjust the pitch or loudness of your voice, change your breathing patterns, or alter the way you produce speech sounds. The SLP will then help you learn to use these techniques in your everyday speaking activities to improve the way your voice sounds and the way it feels when you communicate with your family, friends, and colleagues.

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Rosemary A. Lester, M.A., CCC-SLP, is a doctoral candidate in the Department of Speech, Language, and Hearing Sciences with a minor in Neuroscience at the University of Arizona. She received her clinical training in speech-language pathology at Indiana University and works as an SLP in Tucson, AZ.

“Recent research has demonstrated that therapy can help make the voice sound more stable and make it feel easier to speak.”
Marijuana and Tremor

By Monique Giroux, MD

The acceptance of medical marijuana is growing and so is interest in marijuana for tremor and other brain conditions. To date, 20 U.S. states have legalized medical marijuana and 13 more have pending legislation. Marijuana is known for its beneficial effects on pain, chemotherapy related anorexia and nausea, anxiety and muscle spasms. The role of marijuana in brain disease is just beginning to be explored.

The growing interest in marijuana for tremor is not surprising since traditional medical therapy often falls short of the desired effect. In addition, tremor can change from moment to moment in response to many personal factors such as the tasks or activities a person is performing, emotional unrest, anxiety or stress. In other words, there is a complex interaction between symptom severity and psychological or physical well-being and a person’s activity. Marijuana can potentially impact one or more of these factors.

As with any treatment, the following questions must be examined when exploring the role of marijuana as a treatment for tremor:

1. Are there direct and favorable biochemical or physiologic effects of marijuana on brain function that can improve tremor?
2. Are observed effects related to other factors such as change in emotional well-being or stress?
3. Are there side effects both immediate and long-term that must be taken into consideration?
4. What is the role of other associated factors such as cost, change in activity or habits, and stigma that may result from treatment?

Scientific Background

Marijuana refers to the dried leaves, flowers, stems, and seeds from the hemp plant Cannabis sativa. This contains the chemical delta-9-tetrahydrocannabinol (THC). THC is only one of over 70 cannabinoid compounds found in the plant, each with different biological effects. Collectively these compounds are similar to natural occurring chemicals such as anandamide that exist in our bodies and make up the brain’s endocannabinoid system important for brain development and function.

These cannabinoid receptors are located throughout the brain especially in regions that influence cognition, pleasure, motor coordination, time and sensory perceptions. High concentrations of cannabinoid receptors exist in the hippocampus (memory), cerebellum (learning and motor coordination) and basal ganglia (motor control.) Activation of these receptors results in the “high” users experience; as well as change in coordination, problem solving, mood and altered perceptions such as paranoia or hallucinations.
Potential Medical Use
Marijuana is self-reported to help people manage symptoms of nausea, loss of appetite, muscle spasm and spasticity, pain and anxiety. Chemical isolates of the marijuana plant have different chemical properties and hence their individual use can be of potential benefit for targeted symptoms. Marinol® is an example of a chemical isolate of marijuana used for a specific medicinal purpose. Marinol® (dronabinol) is synthetic delta-9-tetrahydrocannabinol (delta-9-THC) and an FDA approved medicine for nausea. Sativex® is a mouth spray approved in Europe for multiple sclerosis related muscle spasticity and contains delta-9 tetrahydrocannabinol (THC) and cannabidiol (CBD).

Our understanding of the chemical properties of these compounds is in its infancy, but laboratory research suggests that some of these compounds have brain protective effects. Both THC and CBD are powerful antioxidants exerting neuroprotective effects in research models of head injury and neurodegenerative disease. Cannabidiol (CBD) holds promise for medical use since it does not have the psychoactive affects described with the marijuana plant or THC compound. Cannabidiol has anti-inflammatory, antioxidant and immuno-suppressive properties measured in the laboratory; properties that may be especially important to brain disease such as MS, head injury, Alzheimer’s disease and Parkinson’s disease.

Tremor is a symptom of many conditions including essential tremor, Parkinson’s disease, MS, head injury, metabolic abnormalities and can be caused by some medications. There is limited research to guide the use of marijuana for tremor and even less understanding of how different types of tremor may or may not respond. An early study of five patients with Parkinson’s disease by Frankel and colleagues (1990) showed no tremor benefit after smoking marijuana despite personal accounts of prior beneficial effects. The drug did have an effect on brain chemistry given the drowsiness and euphoria experienced during the study. In 2013, Lotan and colleagues studied 20 people with Parkinson’s disease from Israel that smoked marijuana. (Medical marijuana is legal in Israel). They reported an improvement in sleep, pain, tremor and bradykinesia

Continued on page 8
(motor slowness) 30 minutes after smoking marijuana in clinic.

It is not clear whether the benefits measured in these studies are from a direct effect of marijuana on tremor specific brain chemistry or physiology. Marijuana has a complex neurochemistry with combined psychoactive, behavioral and motor effects which alone or combined can impact tremor. For example, tremor will increase with stress and improve with treatments known to enhance relaxation. Marijuana’s behavioral effects may lead to enhanced relaxation, euphoric mood or mitigate the stress response, and this alone could reduce tremor.

**Marijuana Side Effects**
The use of marijuana will likely increase as more states legalize marijuana and societal attitudes about this drug evolve. Like any drug, marijuana use is not without risk. There are potential negative effects of marijuana and its chemical isolates that are noted below:

**Behavioral Effects**
- Psychoactive effects of marijuana can have negative short-term and long-term consequences. For example, sedation, apathy and depression can worsen with use and exacerbate any sedating properties of anti-tremor medication.
- Marijuana can cause psychosis or altered mental states. The elderly, people with cognitive problems, dementia or mental illness may be more susceptible to experiencing these side effects. The combined risk of marijuana in these populations is unknown.
- Apathy can lead to lifestyle changes or habits such as lower activity and exercise levels, poorer eating habits and social withdrawal which can impact the brain and general health.
- Stress certainly worsens tremor and marijuana may indeed have a positive impact on stress physiology. Since there are risks to using marijuana, other alternatives that combat stress such as meditation, guided imagery, exercise and yoga should be considered as treatments with lower risk and perhaps broader general health gains. These anti-stress techniques should not be overlooked as part of a holistic approach to managing tremor.

**General Health Effects**
- Heart rate is increased by 20-100 percent for up to three hours after smoking marijuana with an increased risk of heart attack one hour after use.
- Pregnancy: Marijuana can alter the developing endocannabinoid system in the brain of the fetus. Consequences for the child may include problems with attention, memory, and problem solving.
- Smoking: The long-term impact of smoke inhalation and chemical particulates on lung function is unknown.
- Stroke: THC causes brain artery constriction and atherosclerosis with may lead to stroke. Whether this is true for all users is unknown.

**Other Effects**
- Medical marijuana is legal in some states but is still an unregulated drug with associated risks including potency, contamination and impurities. Synthetic marijuana is often laced (added without the consumers knowledge) with other psychoactive compounds to increase the users “high”.
- Addiction and long-term use: About nine percent of users become addicted to marijuana. Younger individuals and daily users have an increased risk. Withdrawal symptoms include...
irritability, sleeplessness, decreased appetite, anxiety, and drug craving.

- Long-term marijuana use can impact memory, learning, judgment and increase the risk of mental illness such as psychosis or depression and addiction.
- Impaired judgment and motor coordination can double the risk of a motor vehicle accident and this increases substantially if combined with alcohol.

As with any drug, there are pros and cons to using marijuana, and it is important to review these with your healthcare provider. In particular, the potential addictive, psychoactive and behavioral consequences of marijuana use must be taken into consideration. Nevertheless, specific cannabinoids found in marijuana hold promise as therapeutic agents for neurologic conditions offering yet another strategy for treatment, especially when traditional medications have failed or cause intolerable side effects.

Dr. Monique Giroux is co-founder of the Movement and Neuroperformance Center of Colorado in Englewood, CO and medical director of movement disorders for Swedish Medical Center. She is board certified in Neurology with specialized training in botulinum toxin (Botox®) for dystonia, pain and spasticity as well as deep brain stimulation for tremor, dystonia and Parkinson’s disease. She is also medical director of the Northwest Parkinson’s Foundation Wellness Center and project leader for the National Parkinson’s Foundation Care Center Consortium Project. Along with Sierra Farris, PAC, she co-authored Every Victory Counts: Essential Information and Inspiration for a Lifetime of Wellness with Parkinson’s, produced in collaboration with the Davis Phinney Foundation.

References:
Current Research Recruiting

Choosing to take part in a clinical research study is an important decision. Studies going on today may discover the key to understanding what causes essential tremor and new ways to treat it. Research studies offer people an opportunity to try a new therapy that is not available to the general public. Taking part in ground-breaking research is an exciting prospect, but it is important to consider all the benefits and risks of participation before agreeing to be part of any study.

Visit the IETF website’s research page at www.essentialtremor.org/research to learn more about how to choose an appropriate study for you and important things to consider when making a decision to participate.

Here are some essential tremor studies that are currently looking for participants:

**GABA Imaging of Essential Tremor**
Dr. Elan Louis and colleagues at New York’s Columbia University have undertaken a new and exciting research initiative. The objective is to use new advanced imaging methods to learn what is happening inside the brains of people with ET.

If you are interested in participating and learning more, send an email to nch2101@cumc.columbia.edu or call 212.305.8513.

**Ethanol Response in Essential Tremor: Clinical and Neurophysiological Correlates**
National Institutes of Health (NIH) researchers are interested in learning more about the effects of alcohol on hand tremor. The study will be conducted at the NIH Clinical Center in Bethesda, MD. Transportation and hotel costs, as well as a food stipend, will be provided for those who qualify. ClinicalTrials.gov identifier: NCT01200966.

Please contact Gayle McCrossin MSN, RN, CNRN at mccrossing@ninds.nih.gov or 301.443.3471 (TTY: 1.866.411.1010) for further information and to see if you qualify.

**Stereotactic Radiosurgery for Essential Tremor and Parkinsonian Tremor**
The purpose of this study, sponsored by Vanderbilt University in Nashville, TN is to determine the changes in quality of life and degree of tremor for patients with essential tremor or parkinsonian tremor who are treated by stereotactic radiosurgery (SRS). SRS is a form of radiation therapy that focuses high-power energy on a small area of the body. ClinicalTrials.gov Identifier: NCT01734122.

All those interested in this clinical trial should contact Dr. Anthony Cmelak in the radiation oncology department at Vanderbilt at 615.343.2624, as well as Dr. Peter Hedera or Dr. Fenna Phibbs in the neurology department at Vanderbilt at 615.936.0060.

**Brain Mechanisms of Essential Tremor**
Dr. Fatta Nahab, at The Department of Neurosciences at the University of California, San Diego, is conducting a study involving brain imaging using MRI. Participants will undergo a complete neurological exam and psychological testing as part of the study.

If you are interested in participating and learning more, please call 858.822.1399.

**Effects of Octanoic Acid for Treatment of Essential Tremor of the Voice**
Researchers at Syracuse University & Upstate Medical University in Syracuse, NY are studying whether octanoic acid may be useful for reducing tremor when it affects the voice. Researchers are hypothesizing that octanoic acid will reduce the effects of tremor on the voice.
ClinicalTrials.gov identifier: NCT01864525.

Contact Soren Lowell, PhD at 315.443.9648 or slowell@syr.edu for more information and eligibility criteria.

**Kinesia Study**
The specific aim of this study is to evaluate if tremor severity and quality of life can be improved using continuous home monitoring along with traditional assessments versus traditional assessments alone. Study locations are Rush University Medical Center in Chicago, IL and Baylor College of Medicine in Houston, TX. ClinicalTrials.gov Identifier: NCT01978080.

To participate in the Chicago study, contact Teresa Chmura at Teresa_Chmura@rush.edu. For the Houston study, contact Christine Hunter at chunter@bcm.edu.

**Focused Ultrasound Study**
This study is evaluating a new technique for performing Thalamotomy for tremor control. Eligible subjects will be chosen at random to either receive the ExAblate treatment or an ExAblate Sham or “fake” procedure. The chance of randomization to Sham is one out of four. Subjects who are randomized to Sham Control will undergo the same procedure and follow-up visits through their Month 3 visit. After the Month 3 assessments are complete, all subjects will be unblinded. ClinicalTrials.gov Identifier: NCT01827904.

**For more information or to participate, please contact one of these study locations:**

- **Stanford University Medical Center**
  Stanford, CA, United States
  Contact: Ricardo Valenzuela, 650.725.6930 or tremorstudy@stanford.edu

- **University of Maryland Medical System**
  Baltimore, MD, United States
  Contact: Andrea Reddick, 410-328-4723

- **University of Virginia**
  Charlottesville, VA, United States
  Contact: Johanna J. Loomba, 434.243.1435 or FUSbrain@virginia.edu

- **Swedish Medical Center**
  Seattle, WA, United States
  Contact: Amanda Brown, 206.320.3070 or Focusedultrasound@swedish.org

- **Sunnybrook Health Sciences Centre Recruiting**
  Toronto, ON, Canada
  Contact: Maheleth Llinas, 416.480.6100 or Maheleth.Llinas@uhnresearch.ca

- **Tokyo Women’s Medical University (TWMU)**
  Tokyo, Japan
  Contact: Miyoko Naganuma, +81 (0)3.5269.7386 or naganuma.miyoko@twmu.ac.jp

- **Yonsei University Medical Center**
  Seoul, Republic of Korea
  Contact: Eun Jung Kweon, RN, 82.2.2227.4578 or kweonej@yuhs.ac

**Have you participated in a research study? We want to hear your story! Email us at info@essentialtremor.org or call (toll free) 888.387.3667. ©️**
The road unknown: The story of Jean Davidson

Jean Davidson knows motorcycles.

She’s been riding since she was 12, which makes sense given her family history—her grandfather, Walter, teamed up with his two brothers and good friend, William Harley, and started a shop in the Davidson’s 10’x15’ backyard shed, making small motorcycle engines for do-it-yourselfers. That was in 1903.

Three years later, after building and testing their early engine and frame models, the friends built a 40’x60’ shop on Milwaukee’s Chestnut Avenue. In fact, that original site still remains the location of the corporate headquarters of one of the best known and most iconic motorcycle manufacturers in the world today: Harley-Davidson.

Her grandfather was not only one of the four founders of Harley-Davidson, but also the first president. Her father, Gordon Davidson, was company vice president. And for some time, Jean and her husband owned and operated the largest Harley-Davidson dealership in Wisconsin. She had a close relationship with the Harley family, was introduced to many famous motorcycle racers, several infamous Hell’s Angels, and even the daredevil Evel Knievel.
Yes. Jean knows motorcycles.

Although her adventures would leave most of us breathless, there was more that Jean wanted to do other than feel the wind in her hair and the rumble of a throaty engine. Jean wanted to teach.

So she moved away from the hustle and bustle of the family business to a small, quiet town to fulfill her dream. She started teaching high school Social Studies and English and then taught classes in junior high. “It was glorious being an educator”. It was a fun and rewarding career choice, and it filled her heart knowing she was making a real difference in the lives of so many children. She received specialized training in order to teach dyslexic children and adults and eventually started her own learning center in conjunction with Nicolet College, in Eagle River, WI.

And things went on that way, the way things usually do: one day rolled into another and the years drifted by. Before she knew it, she had raised five children and educated countless more. They were the joy of her life, all of them. But as she approached 50, things began to change.

“It was a really stressful time for me,” she said. “I was living in a little town, teaching for a private boarding school and a college. Most of my children were grown and I was thinking about getting divorced. I remember very clearly, as I was driving along and I glanced in the rearview mirror. That’s the first time I noticed it. My head was shaking.”

For some time, she tried to ignore it. She made excuses for it, believing in her heart that if she tried hard enough she could control it—she could will it to stop. But her hands and her head continued to shake, despite her best efforts. “The more I tried to make them be still, the worse they seemed to get.”

Her friends began to notice her hands trembling and her head bobbing. Jean tried to laugh it off, but dear friends can be very persistent. They feared Jean was developing Parkinson’s disease. Jean hoped that wasn’t the case. She knew that her mother had also had shaky hands, but didn’t have Parkinson’s disease. She finally went to a doctor to find out exactly what was happening to her body.

“Have you ever seen On Golden Pond?” her doctor asked her. Of course she had. Katharine Hepburn and Henry Fonda had both just won Oscars for their performance in that film. “Well,” he paused, “you’re going to look just like Katharine Hepburn.” He wiggled his body, shaking his hands as if she didn’t know what a shaking hand looked like. It took everything she had to stay calm. She wondered what exactly he meant by all this. What was this thing she had? How bad would it become? Would she get as bad as her mother? The idea of a shaking voice and head and hands was unnerving, at best.

It took time to get answers, but eventually they came. She educated herself about essential tremor and began trying different treatment options. “I started taking Propranolol. It did okay, but not great.”

There is no tailored treatment for essential tremor. The medications used to treat ET are actually designed to treat other conditions, but over the years physicians have found that these medications help to reduce tremor symptoms. These commonly prescribed treatment options didn’t work for Jean, so she decided to investigate alternative therapies to see if anything else would help control her tremor.

Jean is inquisitive by nature, so seeking out new and different options was nothing new to her. “I tried acupuncture. I thought it would be the answer, but it didn’t make the tremor go away”. The treatments were very expensive and without any real results she stopped going. “So then I started seeing a chiropractor. After six weeks the chiropractor told me (he was so sweet and honest) that he didn’t feel it was making any difference in my tremor.” So again she stopped going. To this day she is reading and researching, looking for new options and noting what does and doesn’t work for her.

In 2001, Jean (and her tremor) was thrown into the public eye when her first book, Growing Up Harley Davidson—Memoirs of a Motorcycle Dynasty, was published. She had spent a number of years gathering personal family stories and old photographs to bring readers a rare look into one of the most famous families in motorcycling history. Overnight, it seemed the spotlight was on her. But instead of speaking to a classroom full of eager students, she was speaking to...
groups of two, three and four hundred hardcore, leather-clad
motorcycle devotees at a time. Not to mention the television
interviews.

Stress and anxiety can exacerbate essential tremor and Jean
faced some difficult moments in front of the camera. When
asked how she managed all the attention and added stress,
her answer was as simple and sweet as her personality, “I try
to make them laugh.” Her gentle nature and down-home
style, which are as visible as her
tremor, are huge assets. “When I
am speaking to a group or in an
interview, I tell them right at the
beginning,” she explained, “I have
essential tremor.” She would then
go on to explain she got her tremor
from her mother, joking that her
mother loved her so much that
she wanted to leave her something
she would never forget. “It always
makes people more comfortable
when they know what it is and
why I shake.” It also makes Jean
more comfortable knowing that
her audience isn’t judging her or
making assumptions about
her shaking.

But Jean’s life was not to continue
on with only laughter. Sometimes
life also brings sorrow.

In 2006, a tragic accident took
the life of her grandson, Ryder.
If you’ve ever been around little
boys, you know that 4-year-olds don’t always follow the rules.
Ryder and another 4-year-old friend from the neighborhood
were playing near the edge of a water-filled ditch; a place
they knew they were not supposed to be near. In a moment,
they both fell into the water. An older boy watched in horror,
frozen with fear. As soon as Ryder’s father realized what was
happening, he jumped in the water searching desperately for
the two boys. He was only able to save the other child. Ryder
was lost. When Jean received the news, she recalled, “I don’t
remember ever shaking so badly.”

The family was devastated, as any family would be at the loss
of someone so young and so precious. The tragedy, however,
sparked something in Jean. It was time to reinvent herself
again. She had already written books about her famous family.
She had even written a few children’s books, with titles like My
Daddy Makes the Best Motorcycle in the Whole Wide World. But
after this loss, Jean knew it was time to go back to her true
love, education. She would find a way to turn this terrible loss
into a tool that could save the lives of countless other children.

Using her background as an
educator coupled with business
savvy and an entrepreneurial spirit,
she established her own non-profit
organization to help children
understand what to do in
危机 situations.

Called “Yell and Tell,” Jean’s
program teaches young children
what to do when they observe
a dangerous situation. Children
often become confused in difficult,
high stress situations because they
fear getting in trouble or being
seen as a tattletale if they ask
for help. Jean’s program teaches
children how to take action when
there is trouble or danger—and
not just the dangers of water.
Her “Yell and Tell” program also
addresses topics such as what to do
about bullies, what should happen
if there is fire, and how to react
around dangerous weapons, just to
name a few.

The program is doing exactly as Jean had hoped. Her website,
www.yellandtell.com, has numerous stories of little “Yell and
Tell” heroes; children who have saved lives, who knew exactly
the right thing to do. They used their voices to yell, tell, and
get help. Their stories are a beautiful tribute to Ryder.

Living with essential tremor can present many challenges,
many speed bumps in the road. But Jean’s example of taking
on challenges—whether it’s overcoming the fear of public speaking, getting a diagnosis you are not sure you want to hear, or turning a personal tragedy into a life-saving tool for children—is a testament to her passion for living life to its fullest.

“Life is so much bigger than having a tremor,” she says. “I say it over and over again…find your gift. That’s what people have to do; they need to find their gift. Find it and develop it. And then, give it back to the world.”

And that is exactly what Jean has spent her life doing, just like her father and his father before him.

Jean may not be a machinist, bike designer, or motorcycle racer, but she is definitely a shining star in the Harley-Davidson family. And there doesn’t seem to be anything that can hold her back, especially not ET.

Jean is a fine storyteller who loves sharing the stories and experiences of her life as a Davidson through books and public speaking. The adventures she has experienced, both in and out of the motorcycling industry, coupled with her enthusiastic, outgoing personality have captivated thousands of people over the years.

You can learn more about Jean on her website www.jeandavidson.com. To learn more about her “Yell and Tell” program, visit www.yellandtell.com.
IETF Scholarship Awards Fall 2014

As part of our mission to support those affected by essential tremor, the IETF awards selected students with $500 scholarships to help lessen the financial burden of attaining higher education. These funds can be used for tuition, books, housing or other school fees and are paid directly to the university, college or trade school.

IETF scholarships are not awarded based solely on outstanding academics, but also on extensive community service and volunteer work. The ability of these students to juggle the responsibilities of their education with service to their communities makes these amazing students out-shine all the rest. We are very proud of their accomplishments and look forward to watching them grow in the future.

IETF: When did you first notice your tremor?
Carilee: I was 9. At the time my family was living abroad in Brazil. My parents were missionaries. My two older brothers, my younger sister and I all attended a private Brazilian school where no one spoke English. Our parents thought it was important that we were immersed in Brazilian culture and the Portuguese language. It was pretty cool.

I have been interested in music and performing since I can remember. But I didn't start performing piano until the age of 7. When I first noticed my hands shaking, I was playing at a piano recital. My hands just wouldn't stop. The other kids asked me about my hands. They asked why I was so nervous. Having done numerous performances already, I knew I wasn't nervous. I didn't feel nervous. But yet my hands were trembling. I was really freaked out. But I didn't tell anyone. I was afraid. I didn't understand what was happening.

IETF: How did your family react to your diagnosis?
Carilee: Both my grandfather and dad are affected by essential tremor. So it wasn't long after I noticed my hands shaking at the recital that my parents noticed too. For a while, they didn't say anything. Like me, they wondered if it was just nerves. But in time they came to realize that it wasn't going away. They explained everything to me and are super supportive.

IETF: How do you cope with your ET?
Carilee. I take medication when I need to, for performances and things. But other than that, I make sure I eat well and try to stay calm. I know that doing certain things like talking in front of the class makes me nervous and makes the shaking worse, so I just do my best to get through it.

But when I perform for an audience I just try to stay focused. I get into a mental zone. Some people may think that I can't do it; that I can't perform with ET. But I can't even describe the joy that I feel when I play piano. Something inside me soars, and I get the complete feeling of rapture and purpose. Nothing makes me happier. And I won't give it up. Yeah, there are some realistic limits because of ET, but I won't give up performing.

IETF: What advice would you give to other young people who are affected by ET?
Carilee: For a while I felt like I couldn't do it. At one performance, my tremor was so bad I almost walked off stage halfway through. But I didn't. Although it was a disaster, I finished the piece. I didn't give up. And I decided right then that I would rather practice piano eight hours a day than do anything else.

I would tell other kids that you shouldn't give up on your dreams. You might have to make some adjustments to the way you do things, but you have to try. You just have to!
IETF: When you first learned that you had ET, what was your reaction?
Carolina: Denial! I felt like having ET was a sign of weakness. I would hide it, ignore it, and pretend I didn't have it. I did whatever I could to try to be “normal”. Not until I was 21-years-old (five years after I was diagnosed) did this all catch up with me.

I had become overwhelmed with life and school. I had a mini quarter-life crisis where I had to stop and question everything that was going on in my life; having essential tremor being one of the biggest issues. I learned two things: first, you can’t ignore something forever because eventually it will catch up with you and you’ll have to face it, and second, when you hide something that is fundamentally a part of you, it messes with you. Emotionally, physically, every part of you starts to fall apart.

Now I wouldn’t necessarily say that essential tremor controls every aspect of my life. No, I may have essential tremor, but that is just one part of me. I am so much more, and will never let having essential tremor stop me.

But for me it got to a point that since I was ignoring my tremor, I was ignoring a part of who I am. I learned that in order to better manage my tremor, I needed to learn all that I could about it. The more I knew about ET, the easier it made it to manage. Now if I had to give a speech or do something that triggers my tremor, I know why my hands are shaking and understand that I have no control over it. So I focus on things I can control.

IETF: Does ET affect others in your family?
Carolina: Nobody in my family has been officially diagnosed, although my mom remembers other family members who would shake, but they have passed away so there is no way of knowing for sure.

IETF: In your childhood, was there ever a time when you felt bullied because of your tremor?
Carolina: As a child I was lucky enough to never experience being bullied because of my tremor. I did a pretty good job of hiding it, so I guess that helped.

I believe the fear of being singled out is more internal than anything else, at least for me. In my mind I created the idea that people were always looking at me, noticing my tremors, judging me and making fun of me. I became my own bully in a way and since it’s all up in my head, I could never escape it. No matter what I did, how much I tried, my own internal voice wouldn’t stop.

It’s a little funny now looking back at it because I’m still pretty close to several of my high school friends. So when I told them that I had essential tremor and what it was, they all said that they had never noticed it. Funny how I beat myself up about something most people, even those close to me, never thought anything about.

IETF: You are currently volunteering as a support group leader for the San Diego, CA area. Why did you want to become a support group leader in your community?
Carolina: Honestly, because I just really wanted to make a difference. It is exhausting constantly having to explain to people what ET is. I want to ultimately create a movement that brings awareness to ET. Also since I have grown up with ET, I have noticed that ET awareness for children and young adults is especially rare. In the future I want to concentrate and focus in on this age group to see how we can shine light on their struggle and help them feel better about themselves and their condition.

For more information about the IETF scholarship program, including submission deadlines and eligibility criteria, please visit the IETF www.essentialtremor.org/about-the-ietf/scholarships.
Scientists Identify Protein Linked to Essential Tremor

In early March 2014, a team of researchers from Université Laval and CHU de Québec, in Québec City, Canada identified unusually high levels of a certain protein in the brains of people suffering from essential tremor. The discovery, the details of which were published in the journal *Movement Disorders*, could lead to an effective treatment for essential tremor.

“Even though it’s not a lethal degenerative disease, essential tremor still poses a serious problem to sufferers, making it extremely difficult to perform basic everyday activities,” explains lead researcher Frédéric Calon, a professor at Université Laval’s Faculty of Pharmacy and affiliated with CHU de Québec Research Center.

Dr. Calon and his colleagues had access to a brain bank developed more than 40 years ago by University of Saskatchewan Professor Ali Rajput to test their hypothesis that the brains of ET sufferers show an overabundance of certain proteins. The researchers focused on two proteins in particular—LINGO1 and LINGO2—which, according to some genetic studies, may be linked to the movement disorder. They measured the concentrations of these proteins in the cerebellums of nine subjects with essential tremor, 10 Parkinson’s subjects, and 16 healthy subjects.

Their analysis revealed that there was a higher concentration of LINGO1 in the cerebellar cortex of people suffering from essential tremor; twice that of healthy subjects. This increase was even more pronounced in people who had been living with the condition for more than 20 years. These differences were not observed in the subjects with Parkinson’s.

“Other studies have shown that LINGO1 slows neuroregeneration following damage to the brain or spinal cord,” points out Dr. Calon, “so we believe that inhibiting this protein could be a promising treatment avenue to explore for essential tremor. The drugs currently prescribed to people suffering from this neurological condition were developed 30 years ago and their effectiveness is limited.”

“This is very exciting news,” says IETF Executive Director Catherine Rice. “The largest obstacle to getting better treatment options is our lack of understanding of what causes essential tremor. This research is starting to unravel the mysteries and will hopefully lead to better more tailored treatments and medications in the future.”

Initial funding for Dr. Calon’s work was provided by a research grant from the IETF. In addition to Dr. Calon, this study’s coauthors are Charlotte Delay, Cyntia Tremblay, Élodie Brochu, Sarah Paris-Robidas, Vincent Émond et, Ali Rajput, and Alex Rajput.

The IETF will continue to follow Dr. Calon and his research team as they continue this important, ground-breaking work.
Coping Tips for Summer Travel

Whether you’re a nature lover or urban explorer, summer is a great time to get out and see the world! However, getting through airport security can be especially difficult for people affected by ET. It can be a frustrating and intimidating experience. That’s why it is important to be prepared!

- Give yourself plenty of time to arrive well before your flight so that you do not have to rush through security.
- When dressing for air travel, wear slip-on shoes that are easy to remove and easy to put back on afterwards.
- Call or go online to review your airline’s security requirements prior to arrival at your gate. Don’t forget to check requirements for your return flight as well. Standards change from airport to airport.

Before entering security:
- Be prepared to empty your pockets of your loose change, keys and cell phone. It is best to carry as little in your pockets as possible.
- Take your belt off (or don’t wear one).
- Have your ID and other travel documents together and in your hand.

The Transportation Security Administration (TSA) offers tips and resources to help the screening process go smoothly and to help you minimize delay. TSA Cares is a toll-free helpline available to assist travelers who have disabilities and medical conditions. You can talk to a representative at 1.855.787.2227 to get more information about screening that is relevant to your specific disability or medical condition.

You are not required to provide medical documentation to TSA security officers. However, some people find it helpful to have medical documentation on hand as a way to discreetly communicate information about their specific needs to security officers. TSA has created a free notification card that you can use for this purpose. You can download a free card at www.tsa.gov.

Travel can be stressful. Here are some tips for how to keep yourself cool, calm and collected during your summer travels:

Avoid caffeine, nicotine, and other stimulants as they will exacerbate your tremor. Even chocolate has caffeine.

Try meditation, deep breathing exercises or yoga to help keep yourself calm and centered.
March marks National Essential Tremor Awareness Month. This year to help raise awareness of essential tremor around the world, the Foundation asked its members, donors, and volunteers to put on their walking shoes and start moving for ET awareness! And boy, did they!

Registrations to walk poured in from all over the country. People were really excited to gather their friends and family, put on their awareness month t-shirts, and take to the streets on March 22 for essential tremor awareness. This year’s walk was very informal, with no set city or pre-determined routes. We simply asked people to get out in their communities and walk and talk about ET. We were not sure how people would react to the idea. However, any concerns we had quickly dissipated as the registrations started arriving. The walk was a simple and easy way for people of all ages to get involved with raising awareness and show their support for those affected.

Several IETF support groups and members participated in the walk, from Indianapolis, IN to Madison, AL. Even our Canadian support group crossed the border to come and walk with their American friends in Michigan! Some walked inside their local malls and fitness centers, while others welcomed spring with a stroll through their public parks and walking trails. We are grateful to everyone who hit the streets to help raise awareness.

Walking was not the only way to get involved in raising awareness. IETF members like Lillian Courtheoux wrote letters to her local newspaper editors in Rochester, NY and sent out press releases to her local media. Others handed out literature and educational information at local farmers markets, like the San Francisco Bay Area support group. Members gave out spiral buttons to friends and family, handed out ET bookmarks, and bought awareness bracelets from the IETF’s online store. Some even requested proclamations from their

Mayor Gregory Ballard kindly agreed to kick off the Indianapolis, IN walk. He stressed how important it is to share information about ET and raise awareness. Since he just learned about ET himself, he said he will issue a proclamation in 2015 declaring March to be ET Awareness Month in Indianapolis.
governors and mayors, asking them to recognize March as Essential Tremor Awareness Month. Several of these proclamations were passed. The governors of both California and Connecticut passed proclamations, as well as the mayors of Palm Desert, CA and the little town of Cherryvale, KS. Whether it’s a huge state or a small town, supporting awareness is vital to helping the public better understand this condition.

March is such an important month. It is our opportunity to get the story of what ET is and how it effects the lives of millions, out in the public eye. It allows us all the opportunity to speak about ET nationally. Many of our members have remarked that although essential tremor is estimated to affect more than 10 million Americans, no one seems to know what it is or they assume it is related in some way to Parkinson’s disease. That is precisely why March is so vital.

Having a nationally recognized awareness month gives us all something to rally behind, to be part of, and to help grow into a larger movement. Every time a letter to the editor is published or someone reads the facts about ET on the back of one of our bookmarks, they become aware. Awareness fosters understanding. And that understanding then leads to compassion. But it takes all of us working together. It takes all of us spreading the word and speaking out about ET. March is the ideal time to do it and help those around us become aware of ET, educated about ET and compassionate to those affected by ET.

The IETF staff and Board of Directors are thankful for everyone who contributed to National Essential Tremor Awareness Month. Together we will continue to raise awareness of this life-altering movement disorder.

Plans are already underway for next year’s national ET walk. Give us a call (toll free) at 888.387.3667 or send us an email to info@essentialtremor.org if you would like to get involved next year! ☺️
Creating Awareness Year Round

We have a shared promise to people with ET to increase awareness and engagement throughout the community and beyond. National Essential Tremor Awareness Month is just one example. March is a time to reach out to friends, family, and neighbors and ask them to help raise awareness for the 10 million Americans living with ET. While March may be over, the time for communities to connect and rally around ET has just begun.

ET awareness can be described as anything you do to help people understand what ET is, that there’s help through the IETF, and how their support could help find better treatment options for those affected. All our awareness efforts combined throughout the year will help rally enthusiasm behind essential tremor research.

Raising awareness throughout the year can be a large or small project or activity. The most important thing is that we keep ET in the forefront everyday instead of relegating it to just once a year. Daily reminders inspire us to keep the conversation going and to increase the number of connections we actually make so ET becomes recognized, better known and understood by the public, our friends and our families.

Below are examples of how you can raise awareness in your community. The impact can be tremendous and help produce involvement and support that makes a difference. So don’t hold back and wait until March of next year. Do it now in anticipation of greater participation in 2015 and grab the power you have inside to inspire others. We all can make a greater difference and we challenge you to join us in continuing to raise awareness each and every day through our actions and words. Don’t be shy; let your voices be heard! It can only create a dynamic outpouring of support next March when we ask for everyone’s support in joining our walk to raise awareness for ET.

Raise Awareness:

- Post messages on Facebook and Twitter about why raising awareness is important to you.
- Write about ET on a blog. Post photographs and video of yourself and your interests and activities to show others that life with ET can still be active and productive but needs to be better understood.
- Send a letter to your editor. Describe how ET affects your life and why it is important that more people become aware of it. Send your letter to your local newspaper, radio and television station editors.
- Ask your local government official to issue a proclamation next year in March, to celebrate ET awareness month.
- Host an ET awareness dinner party, movie night, chili night, dessert night, or wine tasting. Invite family and friends to come over for dinner and a movie. Order in take-out food to keep plans simple.
- Visit www.essentialtremor.org to download free educational materials about ET that you can share with your friends and family. If you don’t have internet access, feel free to call the IETF office (toll free) at 888.387.3667 and we’ll be happy to mail you materials.

Have you had a successful awareness event? Connect with us to share your story. Your ideas will inspire others to get involved in creating more awareness for ET.

Order your free Archimedes’ spiral buttons from the IETF webstore to help spur conversation. www.essentialtremor.org
Each year the IETF attends several healthcare provider conferences, to help educate healthcare providers about ET and the IETF. Reaching out to doctors, nurses, physician assistants, residents and students helps ensure that the most current information about ET is in the hands of those who are most likely to encounter essential tremor patients.

American Association of Neuroscience Nurses
March 8 - 12, 2014
Anaheim, CA

American Occupational Therapy Association
April 2-4, 2014
Baltimore, MD

American College Physicians - Internal Medicine
April 10 - 13, 2014
Orlando, FL

American Academy of Neurology
April 26 - May 3, 2014
Philadelphia, PA

Brain Health Fair
April 26, 2014
Philadelphia, PA
Open to the public (advance registration is encouraged at www.BrainHealthFair.com)

American Association of Physician Assistants
May 26 - 29, 2014
Boston, MA

American Academy of Nurse Practitioners
June 18 - 21, 2014
Nashville, TN

American Academy of Family Physicians
Residents/Students
August 7-9, 2014
Kansas City, MO

American Academy of Family Physicians
Scientific Assembly
October 23 - 25, 2014
Washington, D.C.
Thank you to everyone who established memorials and contributed funds to honor loved ones on behalf of the IETF from Nov. 13, 2013 to March 14, 2014. If your donation was processed after March 14, 2014, it will be listed in the next issue of Tremor Talk. (Honoraria or Memorials are listed in UPPERCASE, donors are listed in italics.)

**Honoraria and Memorials**

**Dona**tions

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**Honorariums**

GERRY & ED BARNETT  
Don & Louise Carter

CAROLYN BARTLETT  
Jewels of Katy

PRESTON BOGGESS  
Bob Bayer & Rozanne Oliver

ERIC & ANGELA BROWN  
William & Diann Brown

NATHAN & LILA BUTTERS  
Charlotte Cohen

MONA BUTTERS  
Nathan & Lila Butters

MR. & MRS. RICHARD COURTHEOUX  
Lillian Courtheoux

NORMA DOHERTY  
Edward & Monica Chuhna Eugene & Marilyn Weaver

COL. & MRS. JOE DRISCOLL  
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LLOYD DUNHAM  
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SHANA ELLIOTT  
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SHARI & STAN FINSILVER  
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STACEY KENNEDY  
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SAM “POP-POP” LEIFRIED  
Noah Patterson

MARGARET LOYD  
Eric & Donna Doerhoff

BRENDA MCCONNER  
Shari & Stan Finsilver

Evan & Lauren Nadler  
Shari & Stan Finsilver

NORTHEASTERN MICHIGAN SUPPORT GROUP  
Ronald & Carol Jerome

COL. & MRS. BARRY PENCEK  
Joseph Driscoll

CAROL POST  
Sue Fenske

STEVE RAIN  
Joann McClure

JACQUELINE SHIMWELL  
James & Ellen Lengel

ZACHARY SHULL  
Shari & Stan Finsilver

BRAD SMITH  
Leo & Beth Wilz

JOAN STEARNS  
Walter Stearns

LYNDA ST. JAMES  
Skip & Dreama Fumia

CECIL & MARGARET TUNE  
Karen Bain

HELEN ZIMMERMAN  
Craig & Michele Barker

**Memorials**

ROSE ALLEN’S MOTHER  
Rose Allen

EDWARD ANTULIS  
Mr. & Mrs. Richard J. O’Malley

CAROLYN A. ARMSTRONG  
Gerald L. Armstrong

JOHN BERNARD  
Betty Erickson Hugh Lackey Martha Law Judith Lipkin Janice Matusevich Patricia Mitchell Lizabetta O’Leary

RAY BOARDMAN  
Estelle Berk

JUNE BRADLEY  
Ann Corless Joyce Hearn Karen & Vince Kavlick Loraine Liscano Bob & Karen McChesney James Stoddard

FRANCES CARLINE  
Michael & Cathy Quindt
Celebrate birthdays, anniversaries or special occasions with a gift “in honor of” family and friends. Or remember loved ones who have passed on with a gift in honor of their memory. Making an honorarium or memorial donation is a great way to recognize those people close to you, while supporting the mission of the IETF.

You can make your donation online at www.essentialtremor.org/donate or by calling the IETF office (toll free) at 888.387.3667.
ET Support Groups: A Community of Caring

By Sharon Alexander & Joe Bremhorst, IETF Ambassadors, San Francisco, CA

When a physical malady turns your world upside down, it’s easy to feel alone. The strength of a support group derives from the simple act of sharing in this common disorder, sharing about our lives with ET. Within a support group problems and set-backs are validated and discussed. Being part of the group makes you realize you really are not alone and that your thoughts and feelings are important to others. It’s a community of caring. It’s truly a gift.

As support group leaders, we seek to draw out these personal feelings by first creating safety within the group. This means that members may share their experiences according to their comfort level. There is no pressure to contribute; it’s fine to sit in the back and just listen and learn. There is something to be said for just being in a room where you know no one is going to ask if you are cold or nervous. It’s a safe place where you can be yourself.

We are fortunate to have a great resource in which to find answers to many of our essential tremor questions, the IETF. The IETF website, essentialtremor.org, has proven to be the definitive source for the latest information on ET. Although many of our support group members have computers and internet access, most support group leaders find it very beneficial to provide printed educational literature at each meeting. We discuss the latest research. We may view a webinar together and then invite feedback. The discussions that take place at meetings are always interesting and informative.

The time we spend at our support group meetings is very important. The meetings provide us all with some great insights. We talk about medicines that helped or didn’t; physicians who strive to understand ET or ones who still refer to ET in terms of a “benign disorder.”

Our support group members also appreciate the times we invite guest speakers to join us. Most recently, we hosted speakers from the University of California-San Francisco, Stanford University, and LiftLab Designs. These meetings allow members to ask questions and get immediate feedback. As one might imagine, when people come together to share feelings of the heart and soul, as well as vital information, friendships develop. It is when we broaden our scope to support each other in our various hobbies and talents that the real growth begins. Our group has shared time together viewing photographs from the Korean War, we’ve attended musical theater, dance productions and art shows, all starring support group members. We send cards (our shaky handwriting in full view) to members who are struggling and have even visited members in the hospital. We have experienced the highs and lows of friendship and have become a family, an ET family.

Seek out a support group in your community and learn more about living your life to the fullest with essential tremor. Every challenge can be met, with a little help and support from your friends.

If there is not an essential tremor support group operating in your area, consider volunteering to start one! Visit www.essentialtremor.org/volunteer to review a position description, training guide and training video. These will help you better understand the responsibilities and benefits of being a support group leader volunteer in your community. If after review, you feel that being a support group leader will fit well into your lifestyle, just complete the online application and the IETF will help get you started!
Gifts Anyone Can Make

Do you know there are ways to support the IETF that don’t affect your current lifestyle or your family’s security?

You can support the IETF with gifts that don’t impact the way you live by designating the International Essential Tremor Foundation to receive estate assets in the future or by making immediate gifts to us of assets that are “out of sight and out of mind.”

We call these “Gifts Anyone Can Make” because anyone can make them now without impacting cash flow, lifestyle, or family security.

The Benefits

• You can make a gift that costs you nothing during your lifetime.
• You can make a gift that leaves your cash flow and current financial planning unchanged.
• You don’t have to use cash to make your gift; you can “buy low and give high” by making your gift with appreciated securities instead.
• You can give an asset you no longer need or want.

Popular Giving Arrangements

• Gifts from Your Will or Trust
• Gifts from a Retirement Plan
• Gifts of Stock and Appreciated Assets
• Gifts of Life Insurance
• Gifts of Real Estate
• Gifts of Personal Property

For more information about these options, speak to your financial planner, visit www.essentialtremor.plannedgiving.org or call us (toll free) at 888.387.3667.

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The IETF recognizes and thanks the members of The President’s Club for their valuable support and leadership. For more information about becoming a member of this exclusive group, call IETF Executive Director Catherine Rice (toll free) at 888.387.3667.

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